Five Minutes with John Dowe
Interview Transcript

Could you tell us a little bit more about the International Mefloquine Veterans Alliance?

Yes, I'm very pleased to be with you today. The International Mefloquine Veterans Alliance was created because of a need to get various Commonwealth and other countries who had symptomatic exposure to the drug while in service, to compare and contrast together their policy with defence and health departments had in regards to the drug. Because they were so concerned about the acute and possible long-term symptoms they were and have been experiencing today.

And of course, we've heard about Mefloquine and how the FDA had to in part revoke their approval and change the packaging. It's Tafenoquine when a safe drug?

We believe that Tafenoquine shares much of the core compound of Mefloquine in that it is derived from the 8-aminoquinoline group. That group has been shown in the past to be neurotoxic, to affect the central nervous systems of a sizable minority of users. So in short, we do not believe Tafenoquine will be or could be properly applied or complied with among service personnel the world over.

When I look at your website, I see three things. I see awareness of the risks, what Tafenoquine is, I see advocacy, trying to lobby and I also see outreach. Could you tell me more about your outreach work?

Yes. In light of the lack of acknowledgement and action to enrol former symptomatic users of those drugs in the military, many individuals are still continuing to suffer in confusion and silence as to what their symptoms may in fact be. We know these 8-aminoquinoline compound drugs, that are neurotoxic, many of the symptoms mimic post-traumatic stress disorder (PTSD) and other issues such as psychosis, depression, suicidal ideation and many of these people just want clarity. Do I have PTSD? Do I have the neurotoxicity from the drug? Am I comorbid with both? With the lack of acknowledgement or outreach, many of these, especially here in Canada, veterans and their families are continuing to suffer and worry.

Is this possible therefore to misdiagnose quinoline poisoning as PTSD?

Yes. We've seen this, especially Dr Nevin, he's been in this fight much longer and has had the greatest exposure and reaching out to the former users. And, yes, they are in fact very much still possibly suffering co-morbid commingled symptoms with PTSD and Mefloquine toxicity, or maybe Mefloquine toxicity in and of itself. Without screening utility for former users be it Veterans Affairs or current military members to apply, we don't have an ability to disentangle what may, in fact, be either existing neurotoxicity. And we know that current and modern traditional PTSD therapies do not apply to someone suffering these neurotoxicity symptoms. It's like treating an arm when you have a broken leg. And so treatment resistance falls in, the person being treated in resistance starts into a cycle of despair, they cannot move forward or increase capacities or functioning, the family members suffer because they bear the brunt of the pain and anguish this person faces daily. Sanctuary trauma is a very real amongst these people that are experiencing this lack of clarity about what their existing conditions are. They no longer you institutions that are supposed to provide the duty of care that they expect. And so, therefore, this outreach and what we do with advocates is to get the word out, the new science the understanding of where we are and to get these people actively enrolled in a longitudinal study etc. are the screening process to give them greater clarity on their health today.

Do you know how far wide these symptoms are? Because, from speaking with Professor James McCarthy, he seems to think that it's a small number of individuals who are affected by neuropsychiatric side effects.

Yes exactly, and I don't think any reasonable drug to get out there on these Quinolines would suggest it's greater than 50-60 percent. We know it's a sizable minority, but that minority is sizeable, because of the number of years that these drugs especially Mefloquine was handed out outside of product guidelines and state a scope of abuse. That 10-15 percent that we feel do have lingering long-term symptoms and are unaware that now so great amounts of people. And of course it's not just about them, but their families as well. So it's thousands upon thousands over time that have been exposed and should be screened today.

The reason why Mefloquine was given in the first place was because the previous malaria treatment wasn't working and so it was a clinical trial for the soldiers. The Australian army have said that was all unethical, this was above-board and the soldiers were made aware of the symptoms, do you agree with that?

I do not. Many parts of the clinical trials that were done on soldiers with the Australian experience parallel the Canadian experience in Somalia from 1992 to 1993. Then Mefloquine was unlicensed in Canada and there was no proper true informed consent as to what the soldiers were facing to be this trial of this anti-malaria drug. So they were unwitting, they were captive audiences as it were. In some cases, we've heard in the Australian Army they were outright duped into becoming involved in these trials. And then once the trials were underway, proper monitoring, especially in the Canadian case, was not done. The protocols that what was expected were not complied with and adverse events went out the window and many of the soldiers as well faced threat of losing their spot on the tour should they continue or admit to neuro or psychiatric symptoms. So they were stoic and did not speak out. So there wasn't a proper capture of the adverse events on the trial, much like there wasn't in Somalia 92-93. Therefore it invalidates a discovery or the abuse, the gathering information from that trial, it has been invalidated for many factors.

And given what we now know about Mefloquine, how do you feel about the FDA's approval of Tafenoquine. Did they get it wrong?

Well, we've seen with many drugs with the FDA that the drugs tend to pass without too much resistance and then, through the application of pharmacovigilance later on in the market studies and such, more stringent warnings would then be applied to the product monograph. Now, basically we think due to the monetary interest that a couple of companies have with Tafenoquine that that would be their impetus for getting this drug to market and I don't think that they've done the proper clinical trials, as Dr Nevin has spoken of in proper models, such as rhesus monkeys as opposed to rats, they surreptitiously went through the process and the FDA has been known to allow this to occur in the past.

Also, talking about monetary value. We did a piece about Tafenoquine and Mefloquine and it's interesting to watch the GSK webcast for their Q2 Results. Tafenoquine is named fourth as one of their factors driving growth forward so will provide significant financially gain to them. Talking more generally about the future, what needs to be done?

I think there has to be a greater collaboration and cooperation with the eyes and ears that are on the ground. On their own, these advocates that are reaching out and doing their own outreach, as it were, in lack of the government and the drug companies to really see how many people are affected within their community, to find out those that would not speak out because they were worried about their job or their reputation at

work and do that sort of pharmacovigilance from the battlefield, to use that pun. That way they'll have a truer picture of the scope of adverse events that do occur. We find that when we use soldiers and such for trials, you're not going to get an accurate picture as to how they're being affected either neuro or psychiatrically in relation to the way these drugs are and how much of the symptoms can be misattributed to the combat stresses they may be experiencing. We just would like to see proper modelling with the drug in rhesus monkey and we would like to see a greater cooperation with advocates and others to know what they're up to, to work in collaboration with them and to help us if need to provide outreach for symptomatic users in the past.

John Dowe, thank you so much.

I really appreciate your time today, I really appreciate your willingness to listen to us to give us a voice as well. It's such a wonderful thing. Thank you.